

Epilepsy and Seizure Disorders



**A Resource
Guide For
Parents**



Notes

to the Reader

- The information contained in this Guide is not intended as, and is not a substitute for, professional medical advice. A child's medical team should be consulted about all decisions regarding clinical care and treatment. No healthcare industry support was used in the development of this guide.
- Throughout the text, we use the word “child.” Please understand that we use this term to refer to a person of any age between birth and 21 years.
- To access websites from this guide, please type or copy and paste into your browser window. If viewing the PDF version of this file, click on the link to automatically open the website in a new browser window.
- Resources for which we were able to verify accessibility in languages other than English have the following notation included in the contact information:



= materials in language indicated



= staff can speak in language indicated

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Many of the photographs in the Guide were taken at Camp Coelho* (June 2007) and appear courtesy of the Epilepsy Foundation of Northern California, camp staff, and participating families.

* Camp Coelho, coordinated by the Epilepsy Foundation of Northern California, is a six-day overnight camp offered free of charge to children, ages 9-15, with a primary diagnosis of epilepsy. It is held at Camp Wawona in Yosemite National Park. Camp goals are to provide a safe, enjoyable residential camping experience for children with a primary diagnoses of epilepsy; build self-esteem by promoting self-confidence, competency, and social interaction; and to foster independence in a safe environment away from home. For more information, please contact the Epilepsy Foundation of Northern California (see page 9).

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Introduction to the Parent Guide

Dear Parent or Caregiver,

Children are one of life's greatest gifts. As parents, we want to do all we can to nurture and take care of our children. As a parent of a child with epilepsy, also referred to as a seizure disorder, you face the additional challenge of learning as much as you can about your child's special needs. This Guide was written with you in mind. It was written to give you some very basic information, including an introduction to epilepsy and seizure disorders. It is not intended to provide medical advice. Any questions related to the medical treatment of your child should always be addressed to your child's pediatrician/family physician or neurologist.

While this Guide may not provide all of the information you are looking for, it should help you begin your search. Throughout (this Guide), we include information about additional resources that we hope will be useful as you begin this journey – a journey that is likely to evolve as you become more knowledgeable about your child's condition. Clearly, not every parent needs or looks for the same information. Use the information that applies to you and your child.

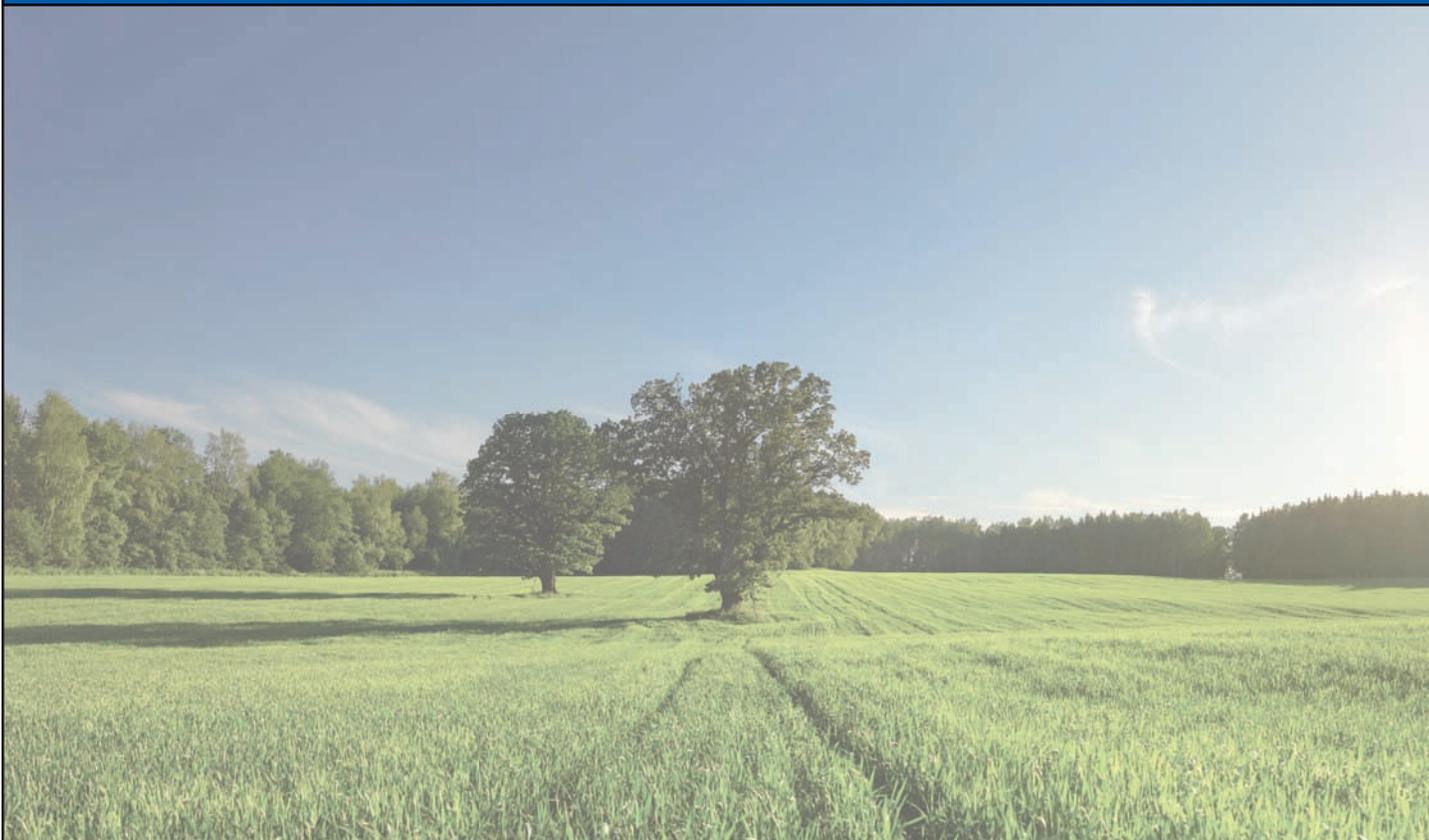
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Understanding Epilepsy/Seizure Disorder



"Seizures are not a mental health disorder. Instead, epilepsy is a neurological condition that is still not completely understood."



What is epilepsy/seizure disorder?*

The brain contains billions of nerve cells called neurons that communicate electronically and signal to each other. A seizure occurs when there is a sudden and brief excess surge of electrical activity in the brain between nerve cells. This can cause abnormal movements, change in behavior, or loss of consciousness.

Seizures are not a mental health disorder. Instead, epilepsy is a neurological condition that is still not completely understood.

Having a single seizure does not mean that a child has epilepsy. A child has epilepsy when he or she has two or more seizures without a clear cause, such as fever, head injury, drug or alcohol use, or a virus (such as encephalitis or meningitis).¹ About three million Americans have epilepsy. Of the 200,000 new cases that develop each year, up to 50% are children and adolescents. About 300,000 children under the age of 14 in the United States have this condition. It develops in children of all ages and can affect them in different ways.²

What are the different kinds of epilepsy/seizure disorder?

There are many kinds of epilepsy and seizures. They each cause different behaviors and they each need different treatments. Identifying the type (or types) of seizures will help your child's doctor suggest treatment options.³

Generalized Seizures

In a generalized seizure, the abnormal electrical activity affects the entire brain. These seizures produce muscle twitches, convulsions and loss of consciousness. People with this type of epilepsy do not remember having a seizure.

Partial Seizures

This type of seizure involves only part of the brain. Sometimes a partial seizure can spread to involve the whole brain. This is known as a partial seizure that secondarily generalizes.

The following chart⁴, contains more information about the different types of generalized and partial seizures. Also see pages 17-18 for information about first aid and safety specific to seizure type.



* Some people use the term "seizure disorder" instead of "epilepsy" to describe this condition. In fact, both terms mean the same thing – an underlying tendency to experience seizures.

Generalized and Partial Seizure Types

Seizure Type		Description
Generalized	Tonic-clonic or Grand Mal (loss of consciousness)	This is the most common and recognized generalized seizure. The person becomes stiff and falls to the ground. Their teeth clench and the arms (usually the legs, as well) begin to jerk rapidly and rhythmically. The seizure usually lasts no more than a few minutes, after which the jerking slows and stops.
	Absence or Petit Mal (loss of consciousness)	During an absence seizure it might seem like the person is daydreaming. However, in an absence seizure the person cannot be made alert or woken up. They are unconscious for a moment and totally unaware of what is happening around them. These seizures usually last a few seconds.
	Myoclonic or Jerks (no loss of consciousness)	Myoclonic means a jerking or twitching of a muscle. During this seizure brief shock-like jerks of a muscle or group of muscles occur. These usually involve the neck, shoulders and upper arms. Myoclonic jerks occur most frequently in the morning and often occur in clusters. Although the seizures are brief, they can be extremely frustrating, resulting in spilt drinks or similar incidents.
	Tonic and Atonic (loss of consciousness)	Tonic seizures result in all muscles contracting. The body stiffens and the person will fall over if unsupported. Atonic seizures, in a way, are the opposite of tonic seizures. Instead of the body going stiff, all muscle tone is lost and the person simply drops to the ground. Although the person falls heavily, they are usually able to get up again right away. When the body goes limp, it inevitably falls forward causing potential head injuries.
	Status Epilepticus (loss of consciousness)	This event is characterized by frequent, long-lasting seizures without regaining consciousness between the start and end of one or more seizures.
Partial	Simple (no loss of consciousness)	In these types of seizures, even though a person's consciousness is not impaired, it does not mean that the person experiencing this type of seizure is able to stop or control the seizure. Simple partial seizures can be different depending on where in the brain the epileptic activity is occurring. Examples of symptoms are the movement of a limb, tingling, experiencing a smell or taste, and going pale or sweating.
	Complex (impaired consciousness)	Because a person's consciousness is impaired in this type of seizure, the person will not remember the seizure or their memory of it will be distorted. Others may believe the person is fully aware of what they are doing, but they are not. Usually the person loses awareness and stares blankly. Most people move their mouth, pick at the air or their clothing, or repeat other purposeless actions. These movements are called "automatisms." Complex partial seizures usually last between 30 seconds and 2 minutes.

How is epilepsy/seizure disorder diagnosed?

Your doctor will ask a lot of questions when trying to diagnose epilepsy and determine the type(s) of seizures your child is having. The diagnosis is based on several exams and tests, in addition to an interview about your child's condition. The facts you provide the doctor are very important in diagnosing your child's epilepsy and deciding on treatment. The following chart⁵ outlines some of the tools a doctor uses for diagnosis.

Tools for Diagnosis		
Interview	Information about Seizure(s) The doctor will ask for a complete description of what happened.	Questions that may be asked: <ul style="list-style-type: none"> • What circumstances surrounded the seizure? • What seemed to bring on the seizure? • What happened before the seizure? • How did your child feel before, during and after the seizure? • Description of seizure behavior? • What happened after the seizure? • Where was the child when the seizure occurred?
	Medical History	You may be asked about: <ul style="list-style-type: none"> • Family history of seizures • Medical conditions or medications • General medical history of your child
Physical Exam	An examination of muscle strength, reflexes, eyesight, hearing and ability to detect various sensations are tested to better understand the cause of the seizures.	
Interview	EEG (electroencephalogram)	An EEG measures the electrical impulses in the brain. During an EEG, electrodes (small metal disks) are attached to specific locations on the head and monitored. Abnormal electrical spikes indicate seizure activity.
	CT or CAT Scan (computerized axial tomography)	A CT scan is an X-ray of the brain that creates three-dimensional images of the brain and shows possible abnormalities.
	MRI (magnetic resonance imaging)	An MRI is another imaging method using magnets instead of X-rays. MRI tests provide detailed images of the brain. CT or MRI scans may be used to search for any growths, scars, or other physical conditions in the brain that may be causing the seizures.
	Blood Tests	Tests to measure white blood cell count, blood sugar, sodium, calcium and electrolyte levels, and liver and kidney function. Blood tests also help rule out other illnesses.
	Other Tests	Other tests may be ordered as needed.

What causes epilepsy/seizure disorder?

Many parents wonder if they have somehow caused their child's epilepsy. They search for a way to understand why this is happening to their child. But it is unlikely that a parent or anyone did anything to cause the epilepsy.

Finding the cause of epilepsy is difficult. For seven out of ten children with epilepsy, there is no known cause. These children are said to have idiopathic epilepsy. "Idiopathic" means "of unknown cause."

However, there are many known causes.⁶ Understanding and identifying the causes help to diagnose the type(s) of epilepsy. Possible causes include the following:

- Problems with brain development before birth
- Lack of oxygen during or following birth
- A serious head injury that leaves a scar in the brain
- Unusual structures in the brain
- Tumors
- A prolonged seizure with fever
- The after-effects of severe brain infections, such as meningitis or encephalitis
- Genetic factors

What might trigger a seizure?

Some people report very specific triggers or immediate causes that can bring about a seizure. Children with epilepsy are more likely to have a seizure (have a lower seizure threshold) when they have a cold, the flu, or other common illnesses. Some common seizure triggers include the following:

- Forgetting/unable to take medication
- Not enough sleep
- Food allergies
- Stress
- Flashing lights (e.g., from video games, strobe lights)
- Alcohol
- Illicit drugs
- Dehydration
- Poor diet
- Inactivity

What are the treatment options?

Childhood epilepsy is usually treated with medications that prevent seizures. If the medications do not work or if the child has too many side effects, there are other treatment options. These include surgery, the ketogenic diet, or vagus nerve stimulation (VNS). Other treatment therapies are being tested, but have not yet been FDA approved.

Medication

Children often take the same antiepileptic medications as adults. Medication may be in the form of tablets, sprinkles, capsules or syrup.

These medications are designed to prevent seizures. Some are successful with a few seizure types; others have a broader range of action. Whenever possible, doctors try to control seizures with one medication. Some children, however, may need to take more than one.

Children may respond so well to medication that no further seizures occur as long as the medication is taken regularly, as directed by the doctor. If seizures are controlled, this may be a result of medicines. Do not stop taking medicines just because your seizures are under control. Always ask the doctor before stopping a seizure medication. Doing so without medical supervision may result in a seizure or another type of reaction.

There are recent concerns regarding differences between brand and generic medications, and different manufactures of the same generic medicine. For more information about these concerns, medications, and medication side effects, contact your doctor or the Epilepsy Foundation at 1-800-332-1000.

Ketogenic Diet

If medications do not control a child's seizures, a doctor may recommend a special high fat, low carbohydrate diet called a ketogenic diet.

Carbohydrates are strictly limited and parents have to be very careful that the child only eats foods that are allowed on the diet or have been pre-measured/pre-weighed.

The diet requires a team effort - the family, the physician, the dietitian, the nurse, and, if the child is old enough, the child himself/herself - all working together to make sure the diet is followed and any side effects are monitored.



Warning

The ketogenic diet is not a do-it-yourself diet. It must be monitored by a medical team.

Medication Tips

- Make sure that you understand the dosages of medicine prescribed by your child's doctor such as the number of pills or teaspoons required for each dose as well as the number of doses and times (e.g., morning, noon, night) to administer each dose. Also, make sure that you understand the best method for administering each medication (e.g., by dropper, mixed with food or liquid, or crushed).
- Ask your doctor or pharmacist about possible side effects associated with each medication your child is taking and what you should do if they occur.
- Keep follow-up appointments. Some medications require periodic blood tests that are important to your child's health. Ask the doctor at the end of each visit when he or she wants to see you both again, and schedule the next appointment.
- Don't change the dose or stop giving seizure medication on your own without first talking with your child's doctor.
- Ask for refills from your pharmacy several days before the medication is due to run out.
- Ask your doctor or pharmacist about over-the-counter medications as they may interfere with the epilepsy medication your child is taking. Also, check with the pharmacist when filling other prescriptions for your child.
- Ask your doctor how to handle fever associated with childhood illness. Ask, too, about the best way to give medication when a child has a stomach virus and cannot keep medication down.
- Find out what you should do if your child misses a dose. Ask whether the dosing schedule is flexible and what to do if your child is scheduled for a dose when he/she is sleeping.
- Do not allow yourself to run out of medicine. It is important that anticonvulsants be given steadily.
- Make sure that the instructions written on the bottle reflects the newest change(s) by your doctor. Always check the expiration date on both the prescription and the bottle.

Vagus Nerve Stimulation

us.cyberonics.com/en/vns-therapy/

Vagus nerve stimulation (VNS) is a type of surgical intervention that may be tried when seizures cannot be controlled by other methods.

The treatment works by sending regular small bursts of electrical energy to the vagus nerve, a large nerve in the neck that leads directly into the brain.

The energy comes from a small disk-like generator, about the size of a stop watch, surgically implanted under the skin on the chest.

The generator is connected to wires under the skin that are wrapped around the vagus nerve. The VNS is put under the skin by a surgeon.



Specialized Care

Specialized care for children with refractory (difficult to treat) epilepsy is available at special centers around the country. Many offer in-depth evaluations, surgery, the ketogenic diet, and VNS therapy. For information about sources of specialized care near you, call the National Association of Epilepsy Centers at 1-860-586-7505 or any other organization listed on page 15.



Health Care for My Child

Access to Care / Access to Services



“The most important way to help your child and his or her physicians is to be an active member of your child’s health team.”



What do I need to know about taking care of my child?

The most important way to help your child and his or her physicians is to be an active member of your child's health team. This means being prepared for visits, keeping records, learning to ask questions and advocating for your child. Networking with other parents of children with epilepsy may become a source of information, strength, and inspiration as you learn to live with your child's epilepsy. And most of all, do not forget to take care of yourself – after all you are your child's number one advocate and they need you.

Make observations

It can be very frightening to see your child having what appears to be a seizure. However, it is important to remain as calm as possible so you can describe exactly what happened to the doctor. It is unlikely that your doctor will ever see your child have a seizure. Your observations and knowledge of your child are vital in helping the doctor reach a diagnosis. It is a good idea to write down these and all observations about the seizure or subsequent behavior so that you can tell your doctor exactly what happened. Two examples of forms to help you track this information are included in the Appendix section of this *Guide* (*Seizure Log* [F1] and *Seizure Description Sheet* [F2]). If possible, try to record a video of your child during a seizure so that your child's doctor can observe exactly what happens and what steps you take in response. Make sure that you or someone is still tending to your child and the seizure during the taping, keeping your child's health and safety a priority at all times.

Educate yourself - ask questions

It is perfectly normal to feel overwhelmed and confused when first learning about epilepsy. But if you ask lots of questions and gather as much information as you can, you are choosing the most effective way to help your child. Learning as much as you can about epilepsy will build your self-confidence and improve your ability to respond to your child's needs. In this *Guide* you will encounter many internet resources, as well as physical addresses and phone contact information. If you do not have a computer with internet access at home or work, you can go to your local library and use one of their public computers to look up the links for free. If you live in a rural area with no library, please contact the Epilepsy Foundation at 1-800-332-1000 for assistance.

You must be your child's advocate. Ask for what you want from doctors. Put everything in writing. You may find friends and advocates at the school district, the doctor's office, or at an Early Intervention program that can help you. If you are not satisfied with the services you receive

from your health plan, medical group, or provider, talk to them about your concerns. If you are still not satisfied, document your concerns in writing. Sample letters can be obtained from your family resource center (see page 20) or online (www.hrh.org – click on Private & Employer Insurance and scroll down to Health Rights Hotline Action Guides).

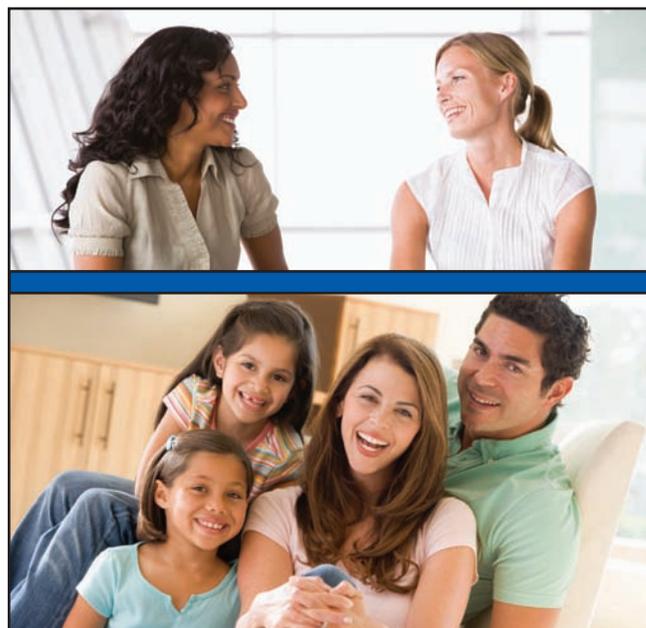
There is a wealth of information available about epilepsy in children. There are organizations on the national, state, and local level that can direct you about who to call and where to look for the information you need. There are books, brochures, websites, training classes, and more to help you find your way and learn about your child and his or her condition.⁶

Get organized

One of the most important things you can do for yourself and your child is to organize information you are receiving. It is very helpful if you have complete medical records available for all the doctors who are treating your child.⁶

Attend support groups and network with other parents

Find support groups for yourself, your spouse, and your family. Take care of yourself to avoid being overwhelmed or getting sick. Your children may sense your stress and it can scare them. You need a place to talk about your fears and concerns. Ask your nearest epilepsy organization about where groups in your area are meeting. Your doctor, nurse, Early Intervention coordinator, or your local hospital may also be able to tell you what associations exist and where support groups may be available. If you go online to a chat room, be sure that there is a medical moderator in the chat room.



Take care of yourself

As parents, our needs always seem to come last. However, we cannot continue as effective caregivers if we do not take time to care for ourselves. Giving all that we can to our loved ones requires taking care of ourselves first. Here are some basic tips⁷:

- Schedule time for yourself each week — take a walk, read a book, take a yoga class, indulge in a makeover, or even go shopping. Take the time to do something that makes you happy.
- Stay in touch with yourself. Keep a journal in which you can express feelings and thoughts.
- Stay in touch with friends.
- Try to eat healthily and stay physically active to prevent chronic disease.
- Look your best. Although it takes energy, it also boosts your spirit.
- Accept help – extra hands at doctors’ appointments, grocery shopping, child care, car pool, etc.

Also, parents may benefit from mental health counseling services and are encouraged to bring up their mental health concerns (e.g., depression, anxiety) to their primary health care provider.

Tips for Caregivers

The following websites have some great tips:

www.americanheart.org/presenter.jhtml?identifier=3039889

www.epilepsyandmychild.org

www.epilepsyfoundation.org/projectaccess/

What organizations can help me find the help we need?

The following organizations can help direct you to information and services in your area:

Epilepsy Foundation

8301 Professional Place
Landover MD 20785-2238
1-800-332-1000

www.epilepsyfoundation.org

Spanish:  

Epilepsy Alliance of Orange County

1500 Adams Ave., Suite 314
Costa Mesa, CA 92626
1-714-557-0202

E-mail: info@epilepsyalliance.org
www.epilepsyalliance.org

Spanish:  

Epilepsy Foundation of Northern California

5700 Stoneridge Mall Rd., Suite 295
Pleasanton, CA 94588
1-800-632-3532

E-mail: efnca@epilepsynorcal.org

www.epilepsynorcal.org Resources > Project Access

Spanish:  

Epilepsy Foundation of San Diego County

2055 El Cajon Boulevard
San Diego, CA 92104
1-619-296-0161

E-mail: info@epilepsysandiego.org
www.epilepsysandiego.org

Spanish:  

Epilepsy Foundation of Greater Los Angeles

5777 West Century Blvd, Suite 820
Los Angeles, CA 90045
1-800-564-0445

E-mail: pleyva@epilepsyfoundationgla.org

www.epilepsyfoundationgla.org

Spanish:  

National Association of Epilepsy Centers

5775 Wayzata Blvd., Suite 200
Minneapolis, MN 55416
1-888-525-6232

E-mail: info@naec-epilepsy.org
www.naec-epilepsy.org

Spanish:  

French:  

How can I pay for or access the care my child needs?

There are services in place to help you find and pay for your child's health care. Private and public programs provide access to services and payment options for those services. Trying to find your way through all the information can be overwhelming to anyone. Someone from one of the organizations listed in the previous section should be able to help.

Local epilepsy organizations may be able to provide the names of doctors who accept private insurance, Medicaid, Medicare, CCS, Healthy Families, Healthy Kids, or doctors who are willing to see patients at reduced rates. They may also know of clinics where care is given free of charge. Online resources offer easy ways to search for doctors, as well.

Here are some of the important programs and service delivery systems (e.g., Managed Care) you will come across as you go about getting care for your child.

Managed Care

Managed Care is a common way that services are delivered under medical insurance plans or Medi-Cal/Medicare. Managed Care links coverage with health care providers in its network. If you have health care coverage through this type of plan, you are an enrollee or subscriber. Enrollees receive their health care from a group of approved doctors and hospitals, called a provider network.

Often enrollees in a managed care plan are assigned to a primary care doctor, or gatekeeper. The gatekeeper's job is to see that the enrollee receives routine medical care such as regular check-ups. The gatekeeper is also the one who decides if the enrollee needs to see a specialist - a doctor or other health care provider who has special training in a particular condition.

The two basic types of managed care plans are Health Maintenance Organizations (HMOs) and Preferred Provider Organizations (PPOs). The main difference between these two plans is that HMOs require their enrollees to receive all of their care from within the plan's network, while PPOs give enrollees the option of using providers either within or outside the plan's network of providers.

Another type of managed care called Exclusive Provider Organization (EPO) is very similar to an HMO. In simple terms, an EPO is a much smaller PPO, offering a very limited number of providers, who offer deeper discounts on their rates because they see a higher volume of patients.

CCS (California Children's Services)

CCS is a program that pays for specialty health care services for eligible children/young adults with serious and/or chronic medical conditions. There is a CCS program in every county in California.

The program is open to children/young adults who meet all of the following requirements:

- Is less than 21 years of age
- Has a CCS medically eligible condition. Not every child/young adult with epilepsy will be eligible for CCS services. He/she must be evaluated by CCS to determine eligibility
- Meets the residential requirements
- Is enrolled in Medi-Cal or Healthy Families programs or has an annual family income of less than \$40,000 or is projected to spend over 20% of annual family income on treatment of the CCS condition

If you think your child might be eligible, call your local CCS office to determine if he/she meets CCS eligibility requirements. To find addresses and phone/fax numbers for CCS offices, go to the website listed below. Links to most county health department websites are also provided.

CCS Directory

www.dhcs.ca.gov/services/ccs/Pages/county_offices.aspx



Mental Health Services for Children

Mental health refers to the successful performance of brain function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and cope with adversity.

Children may require the services of a mental health provider for a variety of reasons; their needs may be related to stresses in the home, family, or school or they may be related to stress or an emotional disturbance associated with special needs and/or learning disabilities. Mental health services are available for children through several different programs. Children who have special health care needs may be eligible to receive services through more than one program, therefore coordination of care is important. The Department of Mental Health (DMH) offers programs to support children enrolled in Medi-Cal and Healthy Families and adults with mental health conditions. In addition, CCS may provide funding for mental health issues related to the CCS eligible condition. Finally, commercial insurance may also include a mental health benefit. Information about this can be obtained from your member services department (check your health insurance card for the number).

For a listing of CA County Mental Health Departments, go to the following website:

CA DMH Listings by County

www.dmh.ca.gov/docs/CMHDA.pdf



Regional Centers

The Regional Center system in California is an entitlement program designed to serve individuals with developmental disabilities regardless of income and to assist their families. Regional Centers serve all ages, from newborns to seniors. There are 21 Regional Centers in the state.

Developmental disabilities, for purposes of Regional Center eligibility, include mental retardation, cerebral palsy, epilepsy, autism and other handicapping conditions related to mental retardation or requiring treatment similar to that required for developmentally delayed individuals. The disability must begin before the person is 18 years old, must continue, or be likely to continue, indefinitely, and must constitute a substantial handicap for the individual. Developmental disabilities do not include handicapping conditions that are solely physical, psychiatric, or related to learning disabilities. To locate a Regional Center serving your area, go to the website listed below.

Regional Center Directory

www.dds.ca.gov/rc/rclist.cfm

Medi-Cal & Healthy Families

California's Medicaid program (Medi-Cal) provides health insurance to low-income families and individuals who lack health insurance. The most commonly used forms of Medi-Cal are:

- Fee-for-service Medi-Cal
- Medi-Cal managed care
- Share of cost Medi-Cal
- Medi-Cal waiver services

For those families who do not have health insurance and make too much money to qualify for Medi-Cal, Healthy Families provides low cost health insurance. Healthy Families offers different plans from which to choose, and includes health, dental and vision care. Small co-payments may be charged for visits.

Healthy Families & Medi-Cal Information

Healthy Families

1-888-747-1222 or

1-877-KIDS-NOW (1-877-543-7669)

healthyfamilies.ca.gov/home/default.aspx

Medi-Cal Policy Institute

www.medi-cal.org

Spanish:  

Medication Assistance Programs

Contact your local Epilepsy Foundation affiliate to learn more about the following list of pharmaceutical companies that are willing to provide medication subsidies to see which group would work best for you. Also refer to www.epilepsy.com/epilepsy/seizure_medicines for the most current list of available medications. The following organizations offer prescription drug assistance:

Partnership for Prescription Assistance

Spanish:  

A partnership bringing together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medications they need, at a discount or for free, through the public or private program that is right for them.

1-888-477-2669

www.pparx.org

Rx Help for Californians

Spanish:  

A website designed to help low-income, uninsured California residents get free or discounted brand-name medications.

1-877-777-7815

www.rxhelpforca.org

Rx Hope

A patient assistance company partially funded by the pharmaceutical manufacturers. It promises to speed requests for no-cost medications. The website includes information about medications covered by assistance programs.

1-800-511-2120

www.rxhope.com/valeant

Access 2 Wellness

Spanish:  

A program that provides access to one of the broadest selections of assistance programs that offer more than 1,000 prescription medications, for free or at a discount, to those who qualify.

1-866-317-2775

www.access2wellness.com

Together RX Access

Spanish:  

A free prescription savings program for eligible individuals/families who lack prescription drug coverage and are not eligible for Medicare, offering 25-40% off medications.

1-800-444-4106

www.togetherrxaccess.com

Rx Assist

A nonprofit group that provides information to health care providers to help patients get medications. 1-401-729-3284

www.rxassist.org



Pharmaceutical Manufacturers

Pharmaceutical manufacturers also provide assistance with prescription drugs for low-income families. Try contacting the specific manufacturers below for details:

Abbott Laboratories

(Depakote)

1-800-222-6885

www.abbottpatientassistancefoundation.org

Spanish: 

Ortho-McNeil

(Topamax)

1-877-937-9682 / 1-800-652-6227

www.access2wellness.com/a2w/patient-pap.html

Spanish: 

Cephalon, Inc

(Gabitril)

1-877-237-4881

www.cephalon.com

Spanish: interpreter available

Pfizer

(Dilantin, Neurontin,

Zarontin, Lyrica)

1-866-776-3700

www.pfizerhelpfulanswers.com

Spanish:  

Eisai

(Zonegran, Banzel)

1-866-694-2550

www.eisai.com/

Spanish: 

UCB Pharma

(Vimpat, Keppra — by Doctor request, Keppra Xr — if over 16 years of age)

1-800-477-7877

www.patientassistance.com/profile/ucbpharma-196/

Spanish: 

GlaxoSmithKline

(Lamictal, Diastat)

1-888-728-4368

www.bridgestoaccess.com

Spanish:  

Valeant

(Diastat, Mysoline)

1-800-511-2120

www.valeant.com/about/programs/patient-assistance-program.jsp

Spanish: 

Novartis

(Tegretol, Trileptal)

1-800-277-2254

www.pharma.us.novartis.com/novartis/pap/pap.jsp

Spanish: 

For a chart of pharmaceutical companies offering assistance programs for epilepsy medications, see *Epilepsy: Patient and Family Guide*, 2nd edition, pages 135-138, by Orrin Devinsky, MD, F.A. Davis Company, 2002.⁸ A 3rd edition became available in 2008.

What is HIPAA?

The Health Insurance Portability and Accountability Act (HIPAA) provides rights and protections for participants and beneficiaries in group health plans. HIPAA includes protections for coverage under group health plans that limit exclusions for preexisting conditions; prohibit discrimination against employees and dependents based on their health status; and allow a special opportunity to enroll in a new plan to individuals in certain circumstances. HIPAA may also give you a right to purchase individual coverage if you have no group health plan coverage available and have exhausted COBRA or other continuation coverage.⁹

HIPPA Information

1-800-368-1019

www.hhs.gov/ocr/hipaa

Spanish:  

The law also gives you rights over your health information. Providers and health insurers who are required to follow this law must comply with your right to the following:

- View/get a copy of your health records
- Have corrections added to your health information
- Receive a notice telling you how your health information may be used and shared
- Decide if you want to give permission before your health information can be used or shared for certain purposes¹⁰
- If you believe your rights are being denied or your health information is not being protected you can do the following:
 - File a complaint with your provider or health insurer
 - File a complaint with the US government

Possible Members of My Child's Health Care Team¹¹

Team Member	Description
Pediatrician	This is a doctor who specializes in the care and treatment of children and is usually the first to see your child for evaluation. This person may also be referred to as your child's primary care provider. This doctor may run some tests and if he or she suspects seizures will probably refer your child to a neurologist.
Neurologist	This is a doctor with special training in disorders of the brain, including epilepsy, and other parts of the nervous system.
Pediatric Neurologist	This is a neurologist who combines a specialty in diagnosing and treating disorders of the brain and nervous system with an understanding of the medical conditions of childhood. Pediatric neurologists, also known as child neurologists, also have a special understanding of the needs of a child and their family. ¹²
Epileptologist	This is a neurologist with speciality training in epilepsy who spends most of their time treating people with this disorder. For routine treatment of epilepsy, it is usually not necessary to see an epileptologist. However, for a child with a seizure disorder that is difficult to treat (refractory), an epileptologist may provide an added level of comfort. If possible, an initial consultation with an epileptologist is advantageous and encouraged in new onset epilepsy. Also, consultation may be beneficial in other circumstances, such as counseling about pregnancy and childbirth.
Neuropsychologist	This is a licensed psychologist with training in the relationship between behavior and the brain and how the two together can lead to brain disorders.
Pediatric Nurse	This is a health care provider who is educated and trained to care for children who are sick or disabled.
Pediatric Epilepsy Nurse	This is a nurse with extra training in pediatrics and neurology.
Nurse Practitioner	This is a registered nurse who has completed advanced training in the diagnosis and management of common medical conditions.

Organizations/Websites List

The organizations and websites listed below offer services to assist you in finding physicians with expertise in epilepsy:

Epilepsy Foundation

8301 Professional Place, East
Landover, MD 20785-2238
1-800-332-1000

Spanish:  

www.aesnet.org/go/find-a-dr/epilepsy-foundation

Use this web address to go directly to the page that offers an online search for doctors near you.

National Association of Epilepsy Centers (NAEC)

5775 Wayzata Blvd., Suite 200
Minneapolis, MN 55416
1-888-525-6232

www.naec-epilepsy.org

The NAEC is a non-profit trade association whose members include more than 60 specialized epilepsy centers.

American Epilepsy Society (AES)

342 N. Main St.
West Hartford, CT 0611-2507
1-860-586-7505

www.aesnet.org

The AES website features a searchable member directory where you can find epilepsy specialists near you.

Epilepsy.com

Epilepsy Therapy Project
P.O. Box 742
Middleburg, VA 20118
1-540-687-8077

www.epilepsy.com

Epilepsy.com provides in-depth and up-to-date medical information and resources for people living with epilepsy.

How can I assure the best health care for my child?

Coordination of care

As more health care professionals are included in your child's health care team, you may feel overwhelmed and confused. Health care professionals have recognized the need to partner with families in caring for children (see Characteristics of a Medical Home below), especially those with special health care needs. For children with epilepsy and their families, such care is therefore ideally provided in a way that feels like a "home". It is sometimes referred to as a "medical home." This is not a building, house, or hospital, but a team approach to providing health care. Your child's primary care doctor or neurologist may assume the role of the "medical home" by taking the lead in coordinating services and helping you to feel connected and supported. The "medical home" is generally the health care provider who best knows your child.

Your role in this partnership is to share your thoughts and concerns, and to be prepared to discuss them, as well as potential solutions, with your child's primary doctor. You will want to ask about your child's medical health care plan (health insurance), medications, referrals, tests and procedures. Other concerns or issues you may want to discuss with your primary care provider may include recreational activities, school concerns, interactions

with siblings, and alternative therapies. Your child's primary care provider should work closely with you and individuals who provide care to your child to assure that all services and supports are coordinated.

Characteristics of a Medical Home¹³

- A partnership between your family and your child's primary care doctor
- A relationship based on mutual trust and respect
- Connections to supports and services to meet your child's and family's needs
- Respect for your family's cultural and religious beliefs
- After hours and weekend access to medical consultation about your child
- Families who feel supported in caring for their child
- Your primary care clinician working with your team of other care providers

Knowing what to do when a seizure occurs

An important way to assure your child's safety is to know what to do when a seizure occurs. Then you will be able to make others aware of the necessary first aid in case your child has a seizure when they are around.

Most seizures are over quickly enough that you do not really have much time to do anything. After it is over, you simply make sure that your child was not injured. Tonic-clonic seizures are the most dramatic and frightening of the seizures, and they usually last longer than other seizures.

CPR is rarely used when a child is seizing. Take a look at the table below to review some basic information that should be considered when responding to a child's seizure.

Please refer to the chart on pages 17-18 for information specific to different seizure types and recommended first aid for each.

Seizure Response¹⁴	
What To Do During A Seizure	<ul style="list-style-type: none"> • Stay calm; most seizures only last a few minutes. • Try to time the length of the seizure. • Move things out of the way so your child will not injure himself/herself. • Lay him/her on one side. • Make your child as comfortable as possible—loosen any tight clothing around the neck and put a pillow or something soft under the head. If they wear eyeglasses, remove them. • Pay attention to the length of the seizure. • Keep onlookers away. • Be sensitive and supportive, and ask others to do the same.
What Not To Do During A Seizure	<ul style="list-style-type: none"> • Do not put anything in the mouth. While your child may bite his or her tongue during a seizure, trying to put something in the mouth probably will not work to prevent this. You may also get bitten, or you may break some of your child's teeth. • Do not try to hold your child down. People, even children, have remarkable muscular strength during seizures. Trying to pin a child with a seizure to the ground is not easy and restraint can lead to more serious medical complications. • Do not give mouth-to-mouth resuscitation until the seizure is over. After the seizure has ended, give mouth-to-mouth resuscitation only if your child is not breathing.
When To Call 911	<p>Most seizures are not medical emergencies, but an ambulance should be called if:</p> <ul style="list-style-type: none"> • The seizure lasts longer than five minutes or one seizure immediately follows another. • Your child does not resume normal breathing after the seizure ends. • Your child was seriously injured during the seizure. • Your child/adolescent is pregnant or has diabetes. • The seizure happens in water, and therefore your child may have inhaled water. • Do not call an ambulance during a typical seizure. For a lot of people, the first response to seeing a seizure is to call 911. But for the vast majority of seizures, that is not necessary. It is also frightening for a child to spend an afternoon in the hospital unnecessarily.
What To Look For After A Seizure	<p>The period immediately after a seizure varies depending on the type, duration, and intensity of the seizure, as well as other factors. Some children may feel discomfort from muscle soreness, headache, and pain in the tongue or cheek if those areas were bitten. Your child may feel confused or tired, and his/her skin may appear pale or bluish. For some, the symptoms after a seizure may be more troublesome than the seizure itself. Antiepileptic medications may not alter the seizures, but can often minimize those symptoms.</p>

First Aid for Generalized Seizures^{15,16}

Seizure Type	What to Do
<p>Tonic-clonic or Grand Mal (loss of consciousness)</p>	<ul style="list-style-type: none"> • Move any hard, sharp, or hot objects away from the child. Put something soft under child's head. Turn child on one side to keep airway clear. • Do not put anything in child's mouth or give liquids or medications during or immediately after the seizure. • Do not try to hold the child's tongue; it cannot be swallowed. • Do not restrain movement. • Cushion the head, remove glasses and any tight neckwear, and turn child on side. Do not restrain movements unless they place the child in danger. Do not put anything in the mouth. If the seizure lasts more than five minutes or if it is the first time that child has had a seizure, you should get medical help immediately. • Reassure the child when consciousness returns. • Usually it is not necessary to call an ambulance if it is known that the child has epilepsy and the seizure ends after a minute or two. • Call for emergency aid if this is the child's first seizure of unknown cause, if multiple seizures occur, if the seizure lasts longer than five minutes, or if the child seems sick, injured, or unresponsive.
<p>Absence or Petit Mal (loss of consciousness)</p>	<ul style="list-style-type: none"> • Observe the child carefully. • Reassure the child if he or she is frightened or confused. • Try to count and record episodes. • No first aid is necessary, but if this is the first observation of an absence seizure, medical evaluation is recommended.
<p>Myoclonic or Jerks (no loss of consciousness)</p>	<ul style="list-style-type: none"> • Speak calmly to the child and other children around him or her. • If the child is walking, guide him or her gently to a safe place. • Stay close until the seizure has ended and the child is completely aware of where he or she is and can respond normally when spoken to. • If the seizure is a first occurrence, a medical check-up is recommended. • First aid is usually not needed. However, a child having a myoclonic seizure for the first time should receive a thorough medical evaluation.
<p>Tonic and Atonic (loss of consciousness)</p>	<ul style="list-style-type: none"> • Comfort the child and check to see if he or she is hurt. A medical check-up is recommended. • No first aid is needed (unless there is injury from a fall), but if this is a first tonic or atonic seizure, the child should be given a thorough medical evaluation.
<p>Status Epilepticus (loss of consciousness)</p>	<ul style="list-style-type: none"> • This condition requires immediate medical attention. Call for medical help. • Do not attempt to transport an actively seizing child in your car unless an ambulance is not available. • If the child has had this type of seizure before, follow advice specifically given by the child's doctor.

First Aid for Partial Seizures^{15,16}

Seizure Type	What to Do
Simple (no loss of consciousness)	<ul style="list-style-type: none"> No first aid necessary, but if this is the first observation of the seizure, medical evaluation is recommended.
Complex (impaired consciousness)	<ul style="list-style-type: none"> Speak calmly to the child and other children around him or her. If the child is walking, guide him or her gently to a safe place. Stay close until the seizure has ended and the child is completely aware of where he or she is and can respond normally when spoken to. Pay attention to the duration of the seizure; most partial seizures last a minute or two. However, a child may be confused for up to half an hour afterwards. Longer periods of confusion may mean that seizure activity is continuing and the child needs medical attention.

How can I make sure others know what to do?

Remember to tell others about the appropriate first aid for your child. Use the *Seizure Action Plan* (form F3 in the Appendix section of this *Guide*) and customize it to fit your child's needs or create your own "what to do" form. Step by step directions should be numbered and should include comforting steps for your child as well as who to call after a seizure. If possible, involve your child in writing these instructions. Hand this form out to babysitters, school personnel, and anyone else who may be taking care of your child. It is important that they be informed about how to handle a seizure and what to do afterwards. Be sure to include how to reach you as well as the telephone number of your child's doctor.

Water Safety

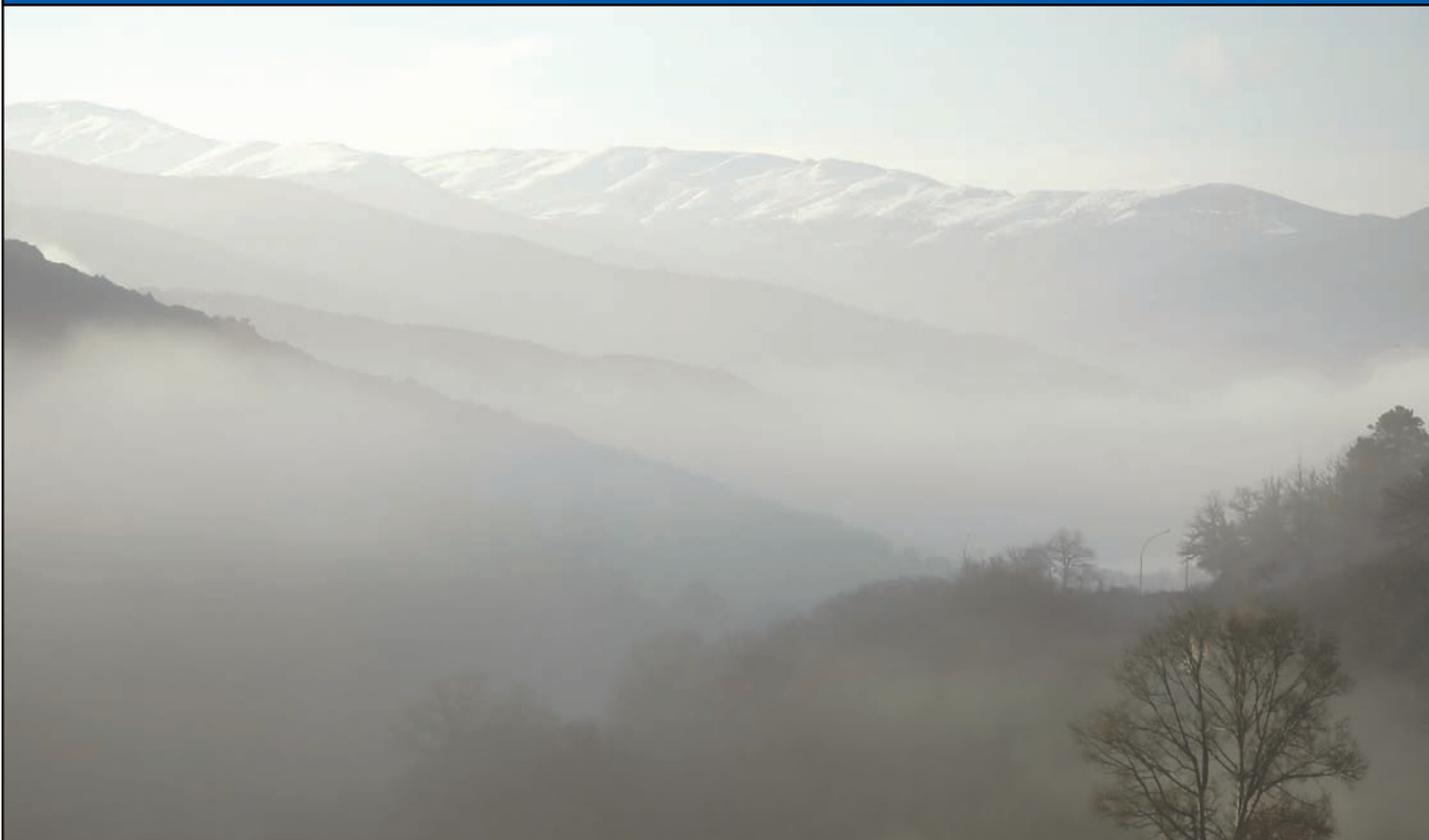
It is very important to **NEVER** leave your child alone in the bathtub or in the pool even for a couple of seconds. This is true for all children, but is especially important for children with epilepsy, as seizure occurrences are not predictable.



Advocacy and Support



“Do not take medical advice from an untrustworthy source and always check with your doctor before trying something new.”



Where can I find support from other parents like me?

Support groups may be in-person, chat rooms (an area on the internet where you can chat with other members), electronic mailing lists (users can subscribe to a mailing list by sending an e-mail note to a mailing list they learn about), or message boards (an application that allows users to post and reply to messages from other users and review the flow of a discussion - also known as a discussion group). Groups can be used to share valuable information about doctors, medications and treatments. The information, experiences and successes gained through each family's journey can be shared to help other families in similar situations.

Always remember that support groups and online groups are made up of other parents like you. Do not take medical advice from an untrustworthy source and always check with your doctor before trying something new.

In-person support

You can find face-to-face support groups and information about counseling for parents by calling your nearest Epilepsy Foundation affiliate or the National Epilepsy Foundation (see page 9) for contact information). You may also want to contact one (or more) of California's Centers designed to help parents. There are three categories:

1. California Family Resource Centers (FRCs):
 - Are part of the state Early Start Program which promotes access to early intervention services for children birth to age three who have, or are at risk for developmental delay
 - Are staffed by families of children with special needs
 - Offer parent-to-parent support, outreach and awareness
 - Offer support for transition out of Early Start
 - Help parents, families, and children locate and use needed services
 - Offer support services, and resources in many languages, which may include newsletters, resource libraries, websites, sibling support groups, warm lines, and information and referral for parents and professionals

Some FRCs have additional funding that allows them to provide services to a broader population such as older children and youth. To locate an FRC near you, go to the website listed below or call the Family Resource Center Network of California (FRCNCA).

FRCNCA

FRC Directory

www.frcnca.org/directory.html

FRCNCA

5775 Wayzata Blvd., Suite 200
c/o Support for Families
2601 Mission Street, Suite 606
San Francisco, CA 94110
1-415-282-7494
email: info@frcnca.org
www.frcnca.org

Spanish:  

2. California Parent Training and Information Centers (PTICs) and Community Parent Resource Centers (CPRCs):

- Parent Training and Information Centers and Community Parent Resource Centers in each state provide training and information to parents of infants, toddlers, children and youth with disabilities, and to professionals who work with children. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. The PTICs and CPRCs work to improve educational outcomes for children and youth with all disabilities (emotional, learning, mental and physical).

PTIC Directory

www.taalliance.org/ptidirectory/index.asp

3. California Association of Family Empowerment Centers (FECs):

- The purpose of the California Association of Family Empowerment Centers is to provide information, resources, technical assistance and systems change advocacy for a statewide network of local FECs who provide family education, empowerment and parent-professional collaborative activities for families of children with disabilities ages 3-22 years old.

FEC Directory

www.cafec.org/find-a-center

As you are looking for specific answers, training, and support, it is important to realize some of the agencies listed above will only provide you with part of the answer you need. Others may be able to give you a more complete answer. In some cases the Parent Resource Center is also funded as a Parent Training and Information Center and as a Family Empowerment Center. Such centers include Parents Helping Parents in Santa Clara, Matrix Parent Network & Resource Center in Novato, Support for Families in San Francisco, Exceptional Parents Unlimited in Fresno, and Rowell Family Empowerment Center in Redding.

Online support

Epilepsy Foundation eCommunities

Here you can interact with individuals affected by epilepsy from around the world through threaded discussions and real-time chats. Select from among the following groups:

- Parents Helping Parents - A group for parents and guardians of children with epilepsy.
- Advocacy - This group discusses various advocacy issues, including local, state, and federal efforts.
- Friends, Family, & Loved Ones - Support for those who give support.
- SUDEP (Sudden Unexplained Death in Epilepsy) - A group for education, support and information sharing about this serious subject.
- The Lounge - An informal place to hang out and get to know other members.
- Teen Group - A place just for teens.
- Entitled2Respect - Straight talk for teens about acceptance and epilepsy.
- KidsClub - The friendly puppy Scoop invites kids of all ages to KidsClub. Come out to the Playground! Visit the Funshop! Read some stories. Play games with the puppy.

www.epilepsyfoundation.ning.com

Epilepsytalk

This electronic mailing list, available globally, is centered on pediatric epilepsy and is designed to benefit families who wish to share comments, concerns, and questions regarding their experiences with pediatric epilepsy and/or other related issues.

www.epilepsytalk.org

Epilepsy Support Group on WebMD

This message board includes discussions about the warning signs of epilepsy or a seizure, which medications are effective, living with the aftermath, and reactions from family and friends.

www.webmd.com/community/boards

Click on *All Boards*, then *Epilepsy: Support Group* or go to:

boards.webmd.com/topic.asp?topic_id=79

Chat rooms on HealingWell.com:

- Epilepsy Forum - Message Boards & Chat - Features interactive message boards and chat rooms. Find support and share information with others.
- Coping With Epilepsy Forum - Discussion forum for anyone affected by epilepsy.
- The Vagus Nerve Stimulation Message Board - Share your experience with VNS.

www.healingwell.com/pages/Epilepsy/Message_Boards_and_Chat

What do I need to know about my child attending school?

Federal laws exist that protect the rights of students to receive a public education, attending schools in their community. The federal law, the Individuals with Disabilities Education Act (IDEA) 2004, states that all eligible children are entitled to a free and appropriate public education (FAPE) regardless of their disability and should be placed in the least restrictive environment (LRE) with proper supports. Many children with epilepsy/seizure disorder have seizures rarely or not at all and are able to participate in all school activities and may require few if any supports. The legal document that defines the supports a child requires in order to benefit from his/her education is called the Individual Education Plan or IEP. Some students who need special accommodations as a result of their medical condition may not require an IEP but instead may benefit from having a Federal 504 Plan. This plan defines those special accommodations that are needed in school, for example, a daily check-in with the nurse for medications or additional time to walk from class to class.

Requests for student evaluations should be put in writing and submitted to the school district director of special education. A parent can request an evaluation by the school

to determine their child's eligibility for special education. The school has 15 school calendar days to contact the parent and to get their consent for testing. Once the consent is signed the school has 60 school calendar days to conduct testing, evaluate results, send the results to the parents, and hold the IEP meeting to determine eligibility. If eligible, this meeting would include development of the child's IEP.

Children who have seizures may be socially isolated at school for various reasons. They may experience self-esteem issues and a lower level of achievement. Fortunately, many of these problems can be addressed and prevented when the school develops a good prevention and education plan. School staff, particularly the classroom teacher and the school nurse, can be educated and provide support to the child and other students to improve understanding. Contact your local Epilepsy Foundation affiliate to schedule a free seizure recognition and first aid training in your child's school. Students can benefit the most when the family and school work together. For example, school personnel and the family can monitor the effectiveness of medication as well as any side effects.

The IEP or 504 Plan is developed by parents and school personnel working together with the student. The services

and supports your child receives are based on his/her individual needs. Schools are required by Federal Law to provide the services in the IEP or 504 Plan. If the school is not providing all of the services outlined in the plan, you and your child have the right to file a compliance complaint by calling the Special Education's Procedural Safeguards Referral Service at 1-800-926-0648.

Additional information for advocates and attorneys can be found in Legal Rights of Children with Epilepsy in School & Child Care at http://98.129.194.75/docs/Legal_Rights_of_Children.pdf¹⁷

For more information on special education, you can get a free copy of "Special Education Rights and Responsibilities" at Disability Rights California (number and website in Resources section on page 23).



Resources - IEPs and the 504 Plan	
<p>California Department of Education www.cde.ca.gov/sp/se/qa/caprntorg.asp</p>	<p>Learning Disabilities Online www.ldonline.org</p>
<p>California Parent Training and Information Centers www.taalliance.org/ptidirectory/index.asp</p>	<p>National Dissemination Center for Children with Disabilities (NICHCY) www.nichcy.org</p>
<p>The Complete IEP Guide: How to Advocate for Your Special Ed Child, 5th ed., by Lawrence M. Siegel Publication information: Berkeley: Nolo, 2007 - ISBN: 978-1-4133-0510-4</p>	<p>Office of Civil Rights www.hhs.gov/ocr/</p>
	<p>Partners in Policymaking www.partnersinpolicymaking.com/ <i>A resource to teach parents and self-advocates to change the way people with disabilities are supported, viewed, taught, live and work.</i></p>
<p>Disability Rights California <i>Special Education Rights and Responsibilities Free legal advice for individuals with disabilities and their families.</i> 1-800-776-5746 www.pai-ca.org or www.disabilityrightscalifornia.org</p>	<p>Spanish:  </p>
<p>Families and Advocates Partnership for Education (FAPE), PACER Center 1-952-838-9000 (TTY: 1-952-838-0190) Email: fape@fape.org www.fape.org or www.pacer.org <i>FAPE aims to improve the educational outcomes for children with disabilities. This website links families, advocates, and self-advocates to communicate the new focus of the Individuals with Disabilities Education Act (IDEA).</i></p>	<p>Sensory Integration Network www.sinetwork.org/home/index.html <i>A website for parents, teachers, and therapists on sensory integration problems. It contains useful information that further explains Dysfunctional Sensory Integration to teachers.</i></p>
<p>Jeanne A. Carpenter Epilepsy Legal Defense Fund¹⁸ www.epilepsylegal.org 1-800-332-1000 Ext. 4 <i>A resource for managed referrals, information, and legal support for families in an effort end epilepsy-related discrimination in the United States.</i></p>	<p>Wrightslaw www.wrightslaw.com <i>A comprehensive website dedicated to special education, including what rights children and parents have, and how parents can advocate for their children. Both IEPs and Section 504 accommodations are discussed. Any question or concern a parent could have about getting needed services for their child is covered. Most content is written specifically for the site by the Wrights, an attorney and a psychologist, both experts in special education.</i></p>

Educating people at school

According to the experts, the best way to prevent misunderstandings about epilepsy at school is to step in early. At the beginning of the year, talk to your child's teacher and school nurse and explain that your child has epilepsy. You may want to take some brochures about the disorder. Getting the right information to the right people at

school early can make a big difference in your child's school experience. Refer to the next section "How can I educate others about my child's epilepsy/seizure disorder?"

There are products available to teach other children about epilepsy/seizure disorder so that students and friends understand more about seizures. You may want to explore some of the resources listed on the following page.

Epilepsy/Seizure Disorder Products

Beach Park

www.epilepsy.org.uk/kids/

Website for kids

KidsClub

<http://www.epilepsyfoundation.org/kidsclub/nonflash/home/index.html>

Website for kids

The Kids on the Block, Inc.

1-800-368-5437

<http://www.kotb.com/kob2.htg/epilepsyfeature.html>

Educational programming (puppet show and curricula).

The Kids on the Block Program on epilepsy was

developed in conjunction with the Epilepsy Foundation.

It addresses a variety of issues surrounding seizure disorders and provides a basic understanding of seizures, demonstrates seizure first aid, emphasizes the importance of supportive and open friendships, and examines issues of discrimination.

The following California Family Resource Centers offer Kids on the Block:

- Parents Helping Parents

408-727-5775

www.php.com

Spanish:  

- Rowell Family Empowerment

of Northern California

1-877-227-3471

www.rfenc.org/index.php

Spanish:  

ask questions. Attempt to remove the mystery around your child and his or her seizures. You may want to hand out a brochure or even a video so they can find out a little more on their own and have time to process the information.

The way in which others are informed affects how they treat your child. This goes for your child, as well. If you learn to talk about epilepsy/seizure disorder, your child will, too. Children are more likely to feel confident about themselves and accept their epilepsy when they know how to talk about it and are not ashamed.

Children and youth with epilepsy must also deal with the psychological and social aspects of the condition. These include public misperceptions and fear of seizures, uncertain occurrence, loss of self-control during the seizure episode and compliance with medications.

Openness and honesty are the best ways to combat any stigma surrounding epilepsy/seizure disorder and you will probably find that most people are empathetic and supportive if they understand the condition and know how they can help.

Please make sure your child is given many opportunities to ask questions and discuss his/her concerns or fears. When possible, he/she also needs to be encouraged to take on some aspects of management of the condition.

You may be getting to know a great deal about epilepsy/seizure disorder, but there are still a lot of people out there who do not. As you educate others about your situation and that of your child, you will help spread the word and reduce the stigma surrounding epilepsy. Please do not take others' lack of knowledge personally.

There are materials available to help make the task of educating others easier. Many find that a good videotape or DVD to hand out to a school teacher or babysitter can help tremendously. For recommendations and to obtain materials, contact your local Epilepsy Foundation affiliate, Parent Training and Information Center (PTIC) or Community Parent Resource Center (CPRC).

Each of the local Epilepsy Foundation affiliates provides seizure first aid training free of charge. Most of the educational resources are free, as well.

How can I educate others about my child's epilepsy/seizure disorder?

Often times you will have to educate others about epilepsy/seizure disorder and your child's condition. It is important to make sure that everyone is aware of what to do when a seizure occurs. But you also want to make others feel comfortable when they are around your child. The more knowledge a person has about epilepsy, the more comfortable he or she will feel around your child therefore creating a healthier environment for your child.

When you explain your child's epilepsy, clearly explain the terminology and then explain in simple terms what this means and how seizures might occur. Encourage others to

For first aid training or any questions about epilepsy or related services, contact

The Epilepsy Foundation of America

8301 Professional Place, East

Landover, MD 20785-2238

1-800-332-1000

www.epilepsyfoundation.org

Sources

Referenced

1. National Dissemination Center for Children with Disabilities (NICHY), Disability Fact Sheet – No.6 (Epilepsy), January 2004. Available at www.nichcy.org/pubs/factshe/fs6.pdf (September 27, 2009).
2. Eric H. Chudler, Epilepsy: Types of Epilepsy. Available at faculty.washington.edu/chudler/epi.html (September 27, 2009).
3. Epilepsy Action (British Epilepsy Association), Epilepsy Information: Seizure Types. Available at www.epilepsy.org.uk/info/chart.html (September 27, 2009).
4. WebMD, Diagnosing Epilepsy. Available at www.webmd.com/epilepsy/guide/diagnosing-epilepsy (September 27, 2009).
5. Epilepsy Foundation of America, Inc., Seizures and Epilepsy, H.O.P.E. Mentoring Program, 2003.
6. Patricia E. McGoldrick and Steven M. Wolf, Parents' Guide: When the Seizures Don't Stop...Why - and What to Do Next (Abbott Laboratories Neuroscience, December 2004). Available at www.wehealny.org/services/bi_pedsepilepsycenter/seizure%20book.pdf (September 27, 2009).
7. Department of Health and Human Services, Centers for Disease Control and Prevention and The Epilepsy Foundation, Reach Out: A Guide for Teens with Epilepsy. Available at www.cdc.gov/epilepsy/pdfs/brochure.pdf (September 27, 2009).
8. Finding a Cure for Epilepsy and Seizures (FACES), NYU Medical Center, Pediatric Epilepsy Resource Handbook. Available at faces.med.nyu.edu/files/faces/u6/Pediatric_Epilepsy_Resource_Guide_12-08-08.pdf (September 27, 2009).
9. US Department of Labor, Health Plans & Benefits, Portability of Health Coverage (HIPAA). Available at www.dol.gov/dol/topic/health-plans/portability.htm (September 27, 2009).
10. US Department of Health and Human Services, Office for Civil Rights, Fact Sheet: Privacy and Your Health Information. Available at www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/consumer_summary.pdf (September 27, 2009).
11. Epilepsy.com, Diagnosis 101: The Basics. Available at www.epilepsy.com/101/101_diagnosis (September 27, 2009).
12. American Academy of Pediatrics, What is a Child Neurologist? Available at www.healthychildren.org/English/family-life/health-management/Pages/What-is-a-Child-Neurologist.aspx?nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token (November 1, 2009).
13. American Academy of Pediatrics, The National Center of Medical Home Initiatives for Children with Special Needs. Available at www.medicalhomeinfo.org/tools/familyindex.html (September 27, 2009).
14. Epilepsy Foundation of America, Inc., First Aid. Available at epilepsyfoundation.org/about/firstaid/ (October 21, 2009).
15. Cynthia Haines, ed., WebMD, Epilepsy: First Aid for Seizures, October 2004. Available at www.medicinenet.com/first_aid_for_seizures/article.htm (September 27, 2009).
16. Epilepsy.com, Treatment: Seizure First Aid. Available at www.epilepsy.com/epilepsy/firstaid.html (September 27, 2009).
17. Epilepsy Foundation of America, Inc., Legal Rights of Children with Epilepsy in School & Child Care. Available at 98.129.194.75/docs/Legal_Rights_of_Children.pdf (October 1, 2009).
18. Epilepsy Foundation of America, Inc., Community P.A.S.S.P.O.R.T. (2006). Available at www.epilepsyfoundation.org/programs/passport/upload/Community%20Passport%20Final.pdf (August 3, 2009).

Appendix:

Forms

There are a variety of forms available to help keep track of seizures and other information about your child's condition. The following pages contain a selection of such forms. Choose the pages that work for you and make copies so you can easily track your child's records. If you would like to print copies from PDF format, access the Guide online at the Epilepsy Foundation of Northern California website:

www.epilepsynorcal.org
(Find "Project Access" under Resources)

These forms are also available in Spanish and Farsi. To obtain a copy, please call the USC UCEDD at 323-361-3830 or access the forms online at the USC UCEDD website.

www.usucedd.org
(Type "Epilepsy Resource Guide" in the SEARCH box)



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Seizure Log

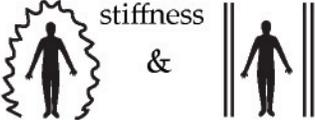
Directions: Use this form to keep track of your child's seizure activity. Your notes will help your nurse and physician in further treatment of your child.

Date	Time Seizure Began	Time Seizure Ended	Current Medication and Dose	Description of Seizure	Any Intervention?

Seizure Description Sheet

Directions: Please check (✓) what happens (or happened) during your child's seizure and bring this sheet to your child's neurology appointment.

Description of Spell or Seizure

Body 	<input type="checkbox"/> whole 	<input type="checkbox"/> right 	<input type="checkbox"/> left 	<input type="checkbox"/> can't tell	
Movement 	<input type="checkbox"/> jerking 	<input type="checkbox"/> stiffness 	<input type="checkbox"/> jerking and stiffness 	<input type="checkbox"/> can't tell	
Eyes 	<input type="checkbox"/> up ↑  <input type="checkbox"/> stare 	<input type="checkbox"/> closed  <input type="checkbox"/> stare and blink 	<input type="checkbox"/> right →  <input type="checkbox"/> no change 	<input type="checkbox"/> left ←  <input type="checkbox"/> can't tell	
Skin Color 	<input type="checkbox"/> blue 	<input type="checkbox"/> no change 	<input type="checkbox"/> can't tell		
Toilet 	<input type="checkbox"/> pee-pee 	<input type="checkbox"/> poop 	<input type="checkbox"/> none <input type="checkbox"/> can't tell		
Mouth 	<input type="checkbox"/> dry 	<input type="checkbox"/> drool 	<input type="checkbox"/> foam 	<input type="checkbox"/> bite tongue 	<input type="checkbox"/> can't tell
How Often 	<input type="checkbox"/> daily	<input type="checkbox"/> weekly	<input type="checkbox"/> monthly	<input type="checkbox"/> other: _____	

After Seizure or Spell

<input type="checkbox"/> asleep 	<input type="checkbox"/> drowsy 	<input type="checkbox"/> alert 	<input type="checkbox"/> confused 	<input type="checkbox"/> paralyzed 
--	--	---	--	---

Seizure Action Plan

This form provides information to assist in the safe care of this child during a seizure

Name: _____ DOB: _____ Age: _____ Age during 1st Seizure: _____
 Parent/Guardian: _____ Home: _____ Work: _____ Cell: _____
 Alt. Contact: _____ Home: _____ Work: _____ Cell: _____
 Primary Doctor: _____ Office: _____ Fax: _____ Alt.: _____
 Neurologist: _____ Office: _____ Fax: _____ Alt.: _____

Seizure Information

Seizure Type	Length	Frequency	Description

Does your child act differently before a seizure? Yes No Explain: _____

How does child act after a seizure is over? _____

How do other illnesses affect child's seizures? _____

Seizure First Aid

In addition to Basic Seizure First Aid, the following procedures should be done when the child has a seizure: _____

Will child need to leave the classroom? Yes No
 Should an extra change of clothes be kept at school? Yes No
 If "yes," where are they kept? _____

 Does child have a VNS? Yes No
 If "yes," when should magnet be used? _____

Basic Seizure First Aid

- Stay calm & track time
- Keep the child safe
- Do not restrain
- Do not put anything in mouth
- Stay with the child until fully conscious
- Record seizure in log
- Turn the child on their side

For tonic-clonic seizures:

- Make sure head is protected
- Keep airway open/watch breathing

A Seizure is generally considered an **EMERGENCY** when:

- A convulsive (tonic-clonic) seizure lasts longer than 5 minutes
- The child has repeated seizures without regaining consciousness
- The child has a first time seizure
- The child is injured or has diabetes
- The child has breathing difficulties

Seizure Emergency

A seizure emergency for this child is: _____

- Administer emergency medication listed below
- Contact school nurse at: _____
- If an ambulance is required, transport to: _____

- Notify parent at: _____
- Notify emergency contact at: _____
- Notify doctor: _____
Doctor's Name Phone

Emergency Medication Plan

Medication	Dosage	Method	When to use

Special Considerations/Safety Precautions _____
 (with school activities, sports, trips, etc.) _____

Doctor Name & Signature: _____

Parent/Guardian Signature: _____

School Nurse Signature: _____

My Child's Profile

Name			
Date of Birth			
Height		Eye Color	
Weight		Blood Type	
Languages Spoken		Sex	<input type="radio"/> male <input type="radio"/> female
Telephone	Home	Work	Mobile
Address			
Parent/Guardian			
Telephone	Home	Work	Mobile
Address			
Parent/Guardian			
Telephone	Home	Work	Mobile
Address			
Emergency Contact			
Relation			
Telephone	Home	Work	Mobile

Primary Health Insurance

Health Insurance Plan			
Plan Number			

Secondary Health Insurance

Health Insurance Plan			
Plan Number			

My Child's Profile (Continued)

Primary and Secondary Diagnosis			
Medical Alerts			
Most Recent Hospitalization History Including Surgeries			
Date	Reason	Name of Hospital	Attending Doctor
Primary Care Physician			Office Number
Neurologist			Office Number
Notes			

Medication Log

Directions: Complete the chart below, listing all medications (prescription, over-the-counter, vitamins and supplements) your child takes. If the directions for a medication changes, mark through that row and begin a new row with updated directions. Be sure to bring this sheet with you to all of your child's medical appointments so you can review the information with your child's providers.

Start Date	Name of Medication	Dosage	Frequency	What is it used for?	End Date	Comments

Doctor's Visit Notes

Directions: Use this form to remind yourself about questions you have for your child's doctor and to record your own notes from the visit.

Date of Appointment		
Doctor	Name	Phone
Before the Visit		
1. Reason for today's visit?		
2. How long has it been going on?		
3. What makes it better/worse?		
4. What have you tried so far?		
5. What do you hope will happen at this visit?		
Notes from the Visit		
1. What is the diagnosis?		
2. Does my child need a prescription? If yes, what is the medication and dosage?		
3. What should the medication do and when?		
4. Is there anything I should watch out for/side effects?		
5. If no medication is needed, what should I do for my child to resolve the issue?		
6. What should I do if my child gets sick or has more symptoms?		
7. Where can I get more information?		

Doctor's Visit Tips

Get Ready

1. Bring any information that you have about your child (My Child's Profile)
2. Bring pen/pencil and paper to take notes
3. Check your data and be specific about all changes in your child's health status (Seizure Log, Seizure Description Sheet)
4. Have a list of all medications your child is currently using, including over-the-counter drugs (Medication Log)
5. Have a list of reactions your child has experienced from any medications, prescribed or over-the-counter
6. Write all of your questions down before visiting the doctor (Doctor's Visit Notes)

Tell the Doctor:

1. How your child has been doing
2. Information about successes and setbacks
3. Detailed information about changes and symptoms that are different from your child's normal status
4. What you are concerned about
5. When the symptoms started changing
6. How often and when the symptoms occurred
7. What you have tried to relieve the symptoms and your child's response

Don't Leave the Doctor's Office Without:

1. Instructions and name(s) for new and old medication(s)
2. Asking how long the child will be on medication and whether there are refills
3. Asking about possible side effects or cross-reactions of medication(s)
4. Asking what the child can eat with new medication(s)
5. Asking if you need authorization before filling the prescription for your specific insurance provider
6. Understanding all follow-up questions including how to report changes in symptoms
7. Asking the doctor if you need a follow-up appointment
8. Making the next appointment, if needed

Encounter Log

Date	Name / Agency & Phone	Purpose	Type	Result
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In person <input type="checkbox"/> Email <input type="checkbox"/> Fax	

Key Contacts

Name	Contact Numbers	Address(es)	Special Notes
Epilepsy Foundation Northern California	Phone: 925-224-7760 Toll Free: 1-800-632-3532 Fax: 925-224-7770	5700 Stoneridge Mall Rd., Suite 295 Pleasanton, CA 94588 Website: www.epilepsynorcal.org	



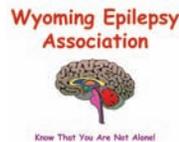
University of Southern California
 University Center for Excellence in
 Developmental Disabilities
 Childrens Hospital Los Angeles



**Childrens Hospital
 Los Angeles**
International Leader in Pediatrics

An electronic version (PDF format) of the Guide
 can be accessed via the Internet at the
 Epilepsy Foundation of Northern California website:

www.epilepsynorcal.org/docs/parent_guide.pdf



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